

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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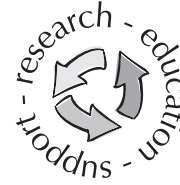
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#### **Aims and Scope**

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day to day matters affecting the lives of patients.

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# The nursing role in managing HIV treatments

Eileen Nixon

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This edition of *HIV Nursing* is focussing on HIV treatments and a number of nurse-led issues relating to the current and future treatment of HIV disease. Nicky Perry is updating us on new and future antiviral drugs and Sharron Brown and Odile Brennan give us an excellent insight into the mechanics of delivering a nurse-led New-Fill clinic. We also have articles from Martin Jones in Eastbourne on the evolving role of community nurse specialists and a peer-reviewed article that examines core psychological problems for people with HIV in the current healthcare climate.

We continue to see more and more examples of nurse-led services that offer treatment management, support and monitoring as the demand on services continues to increase at a rapid pace. In relation to the change in disease management and HIV treatments, nurses are beginning to push the boundaries of practice by applying HIV nursing skills to more advanced levels such as follow-up clinics, adherence support and caseload management.

While I think we all welcome the opportunity to develop nurse-led clinics, it is equally important that nurse-led initiatives are incorporated into day-to-day service delivery when this is possible within existing resources. For example, the joint British HIV Association and British Association for Sexual Health and HIV (BHIVA/BASHH) conference held in Dublin in April 2005, highlighted the current debate on the nucleoside reverse transcriptase inhibitor (NRTI) backbone of choice and it is helpful if nurses are able to engage in informed discussions with patients who may have anxieties about conflicting viewpoints on optimal treatments.

Nurses are also in a pivotal role to identify short-term side effects of antiviral regimens when seeing patients in the clinic or when starting therapy in in-patient settings. Knowledge of common side effects that can lead to potential ill health, such as hypersensitivity reactions and symptoms of abnormal blood parameters, can lead

to more-rapid medical interventions when required. Likewise, skills in assessing long-term side effects of HIV medications can assist in referring patients appropriately to HIV services as opposed to general practice.

The Public Health White Paper [1] has presented us with a range of nursing possibilities in relation to the care of HIV patients. This Department of Health paper was definitely written with nurses in mind and conjures up memories of the activities of the living model of nursing [2]. Yet again, frontline HIV nurses are in an excellent position to assess and advise patients on the fundamentals of public health in relation to diet, exercise and sexual health. We need to look at formalising these interventions during our clinical contacts and maintaining healthy living for those patients taking antiviral treatment as well as for those who are not. In view of the association between cardiovascular disease in HIV patients, irrespective of antiretroviral therapy [3], HIV nurses also need to contribute to assessing cardiac risk factors, patient education and smoking cessation schemes.

As HIV treatments and our knowledge of side effects continue to expand, the role of HIV nurses will inevitably change. Whether this change takes the form of nurse-led clinics or includes new strategies within existing nursing sessions will depend on local circumstances. What matters is that we all try to find ways to make small incremental steps to maintain the safety, longevity and quality of life for patients taking treatments for HIV disease.

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# Development of nurse-led facial lipoatrophy clinics

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## Introduction

**L**ipodystrophy is a distressing syndrome of metabolic and body fat changes associated with highly active antiretroviral therapy (HAART), particularly thymidine analogues such as stavudine (d4T), in HIV-positive patients. HAART is thought to be a contributory factor in body fat loss, or lipoatrophy, which is one component of this syndrome. Facial lipoatrophy is visually disfiguring and may become a stigma of one's diagnosis. Patients with facial lipoatrophy are exposed and have no control over disclosure of their condition. According to current estimates, 20 to 83% of people treated with HAART will develop some form of facial wasting. Until recently, treating facial changes was seen as purely cosmetic. Nowadays, physicians and nurses recognise that these changes have a profound effect upon the patients, their well-being and their ability to adhere to treatment [1-5].

Recent research has shown that treating a patient's facial wasting with a medical device such as New-Fill reduces anxiety levels and improves quality-of-life scores. Anecdotal evidence is encouraging, with patients stating that their lives are improving: 'It has helped me start to fight back to health'; 'It is great being invisible'; 'You have helped me to smile again' [5,6].

We believe this is a unique time for the development of a nurse-led service to achieve good clinical practice and to deal with issues in accordance with clinical governance. Nurses are particularly suited to such a service. Lipoatrophy affects the appearance, which in turn has an effect on the individual's sense of self. Nurse practitioners have the necessary skills to deal with such issues holistically.

## What is New-Fill?

New-Fill is a poly-L-lactic acid (PLLA) that stimulates the production of new collagen in the injected area, thickening the dermis in an area that is depleted of fat. New-Fill is known as Sculptra in the USA where it was approved for use with lipoatrophy by the Federal Food and Drug Administration (FDA) in August 2004. The product can take several sessions to achieve the result required and can continue to grow increased mass for up to 6 months from initial treatment [7].

## Mechanism of action

The action of New-Fill is two-fold. At first it has the effect of volumising the skin in the injected area. This enables the patient to imagine the end result although careful counselling is needed to prepare the patient for the reduction of volume in the subsequent few days following treatment. The secondary action is to stimulate new collagen cell growth over a period of time. This action continues even up to 6 months after injection. The results of two studies, the Chelsea and Westminster 2002 cohort (two groups of 15 patients; in one group New-Fill was administered immediately, in the other group the treatment was delayed by 2 weeks), and the Vega study (50 patients were treated with New-Fill at 2-weekly intervals) in 2001 [5,6], reported the positive benefits, both visually and psychologically, of patients being treated with PLLA to repair facial wasting. These studies only treated the buccal fat pad area (central cheek pad) and although initially the patients who participated were happy with their results they returned saying: 'My face looks better, but could anything be done about my temples'; or 'When I smile my cheeks look too full or unnatural'.

Treatment of lipoatrophy is clearly not just about filling the cheek hollows, but also about achieving as natural a look as possible. Lipoatrophy creates loss of normal facial contour, very much as in the ageing face but in an exaggerated manner. It can de-feminise the female face and it can change the ability of the face to correctly express emotion. Patients often complain that people read their faces incorrectly. All these factors have to be continuously assessed during treatment with New-Fill. Listening to how a patient expresses himself/herself regarding his/her body image and sense of self is crucial.

## Development of treatment

There have been several changes to optimise treatment; most have evolved from patient feedback once a relationship has developed between patient and practitioner. Patients were enjoying the new volume seen in the buccal fat pad area but noticed that the area above looked drawn. By filling the area in the upper cheek first, the skin thickens and allows a natural looking contour to the face.

This injecting technique can be explained at assessment as the reasons for using this technique may not be obvious to the patient at the time of treatment. There are two methods of injecting New-Fill; these are tunnelling and depot. Tunnelling injection technique is a retrograde style of injecting and is best used in the soft tissue area. The needle is introduced deep into the dermis and a trail of New-Fill between 0.01 and 0.03 ml is injected as the needle is withdrawn, stopping before it enters the superficial layers of the dermis. Depot injection technique is used for temples and upper zygoma. These are vascular areas and needle reflux or aspiration must always be performed before injecting any product. The needle must be injected deep into the dermis onto the periosteum of the bone, before aspirating then depositing 0.01 ml of New-Fill and aspirating again. Finally, the needle is withdrawn as this prevents any product being deposited superficially (Figures 1 and 2). Both these injection techniques are specialised and should not be performed without prior training.

The treatment should proceed according to the following sequence of assessing, treating, waiting, assessing again and, if in doubt, further waiting.

#### Assess

- Assess the severity of lipoatrophy. Guidelines can be taken from the lipoatrophy scale devised at the Chelsea and Westminster Hospital (Figure 3).
- Observe facial contours; look at the temples and cheek areas.
- Is there a loss of facial volume?
- Are there any prominent bony landmarks or folds of skin?

#### Treat

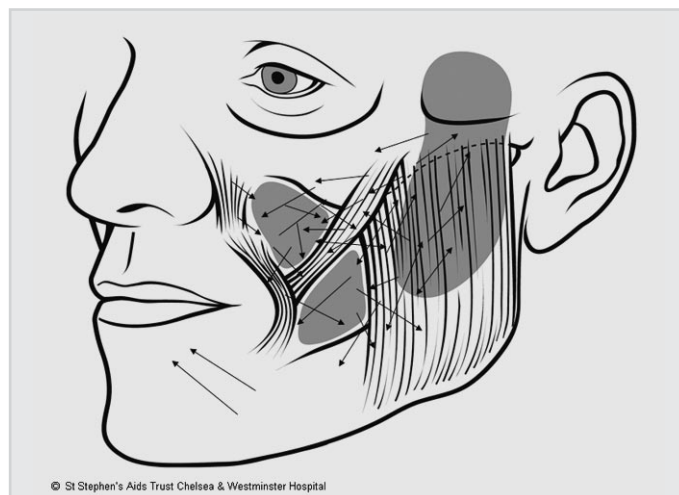
- Using a more diluted mix, reconstitute to 5 ml as this has been found to reduce the risk of palpable lumps [7].
- Treating the upper face, temples and upper cheeks. Treat with a limited correction at each session (we have found that as a result of the mechanism of action of New-Fill, there is what is known as a 'disappointment factor' between the first and second treatments. To shorten this we plan the first two treatments 2 weeks apart.)
- Injecting deeper (depot) especially across the upper zygoma, onto the periosteum of the bone [8].

#### Wait

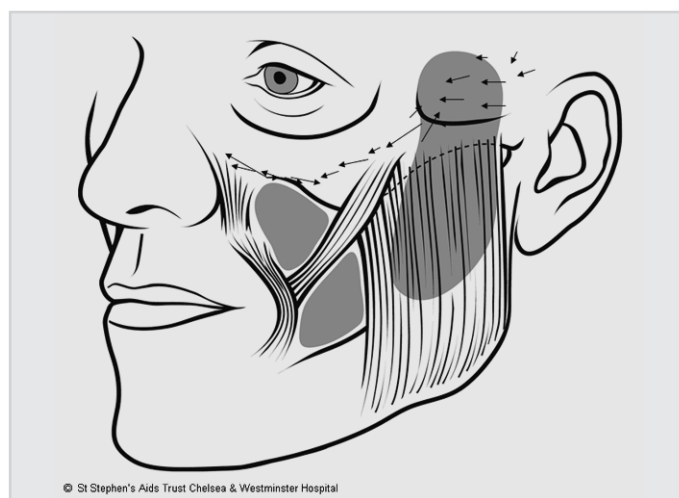
- Wait for gradual dermal thickening; this can take from 3 to 6 weeks.

#### Assess

- Assess the need for additional treatment after a minimum of 4 weeks, apart from the above-mentioned start of treatment regimen.



**Figure 1:** Tunnelling injections for injecting in lower face.



**Figure 2:** Depot injections used for injecting in temples and upper zygoma.

The patient needs to be aware of the importance of massaging the face after treatment.

Skincare, sun protection, hydration (drinking plenty of water) and the importance of a healthy diet should also be discussed with the patient.

### Possible anxieties and emotions

In all people living with HIV, psychological support and maintaining self-esteem is essential to assist managing their diagnosis. Whilst treatment is in progress, the patient embarks on an emotional journey restoring self-esteem and confidence as their face improves.

Often the process can be emotional from the first appointment. The patient may verbalise for the first time their innermost anxieties over this condition and we may need to confirm with them that what they see is actually there, thus validating their feelings. What patients need is a truthful and unpatronising interaction. Let patients talk, listen to their story; they need it to be heard. This needs to be managed realistically timewise as in an assessment consultation you may have only 20 to 30 minutes, but by asking the right questions you should still be

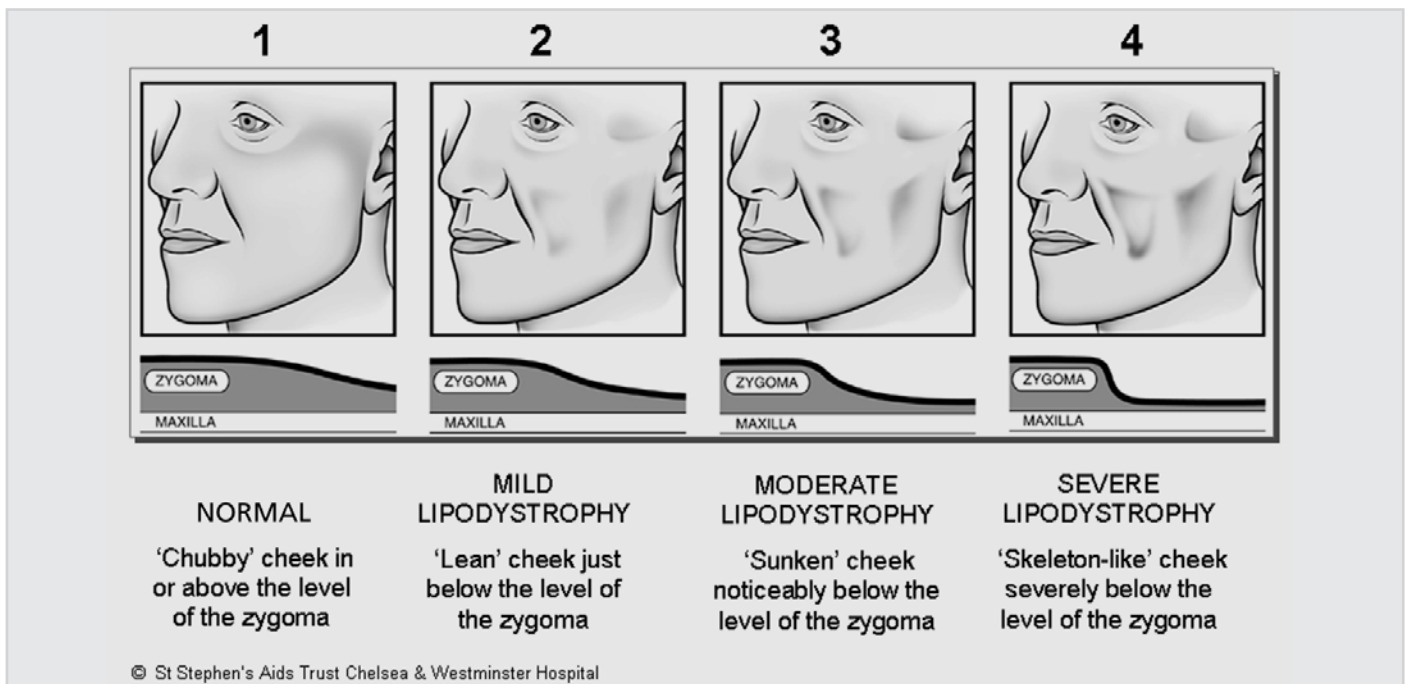


Figure 3: Lipoatrophy scale.

able to assess and evaluate the psychological impact of having the treatment.

It is often a massive relief for the patient to open up to someone who understands how difficult it can be to look in the mirror, have a photograph taken, meet people, family, old friends and new, allow your face to be touched, initiate a new or even continue an existing sexual relationship.

### Treatment process

Starting in the upper face will usually create a natural-looking result. Working across the zygoma and below the level of the zygoma will help to lift any sagging facial tissue in a patient with moderate to severe lipoatrophy. It is important to lift and fill the bony prominent area of the face first as this ensures less heaviness in the lower soft-tissue area when treated. Some patients fear needles; consider breathing techniques to relieve any anxiety or pain. Most practitioners give some form of topical anaesthesia too. The patient needs to grimace, smile and blow out their cheeks to achieve a natural look. Remember faces are not naturally still. They move constantly with conversation and emotion.

Usually four to five treatments are required. Patients are glad of the gradual change in the face as the pace enables them to adjust to a world that not so long ago seemed very hostile.

### Treatment after-care

After-care is important, massaging or manipulating the face after each treatment session helps achieve even distribution. Sometimes getting the patient to

touch his/her face can be difficult especially if he/she has been profoundly affected by lipoatrophy. Sometimes touching the face can only reinforce the negative body image or low self-esteem. Involving patients in the practical after-care of the treatment gives them an active role in the treatment plan as well as getting them to follow a simple skincare regime. Learning to massage or touch the face can also have a nurturing effect, which can be a constructive course of action in this patient group. Patients often report that they feel better having massaged their face.

### Conclusion

This treatment is reconstructive and not cosmetic; and therefore it needs to be considered as such. New-Fill has been proven to be a safe and effective treatment for facial lipoatrophy in HIV-positive patients regardless of the severity of wasting. Patients benefit from the time and focus given to them during treatment sessions as this might be the only arena where they do not have to be on their guard. Nurses are able to address the multi-faceted aspects of facial lipoatrophy and implement appropriate action accordingly, as early intervention helps to counteract adherence issues and psychological distress.

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## New drugs in development

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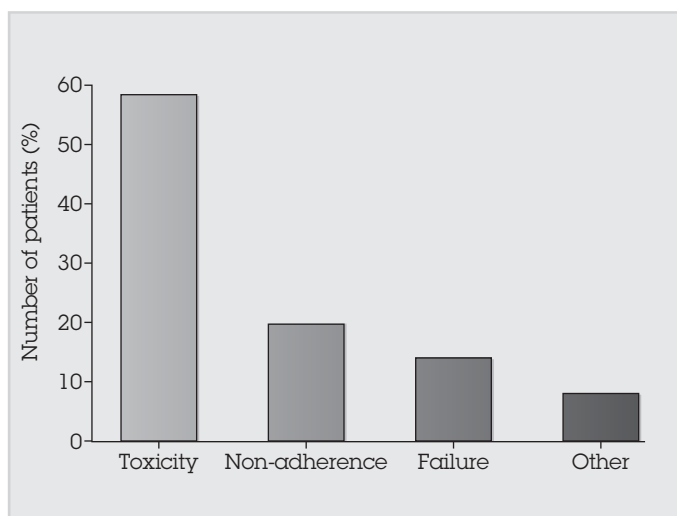
### Introduction

The development of new and improved treatments for HIV infection has significantly altered the natural history of HIV and AIDS. As new drugs against HIV have become available, these have had a dramatic impact on estimates of the average prognosis of people with HIV. The most dramatic developments in HIV treatment have occurred since 1995. There are over 20 licensed antiretroviral agents currently available. If you count alternative formulations and co-formulations of different drugs in one pill, there are now 25 different pills to choose from (Figure 1).

### Why do we need new drugs?

Failure of highly active antiretroviral therapy (HAART) due to resistance is one reason for the discontinuation of a drug or regimen. However, in the Italian Cohort of Patients Naive from Antiretroviral (ICONA) cohort [1] it was a distant third cause of discontinuation. The most frequent cause was toxicity, followed by non-adherence (Figure 2).

Therefore, it is becoming increasingly important to develop drugs that are easy to take, with few toxicities and with a different resistance profile to



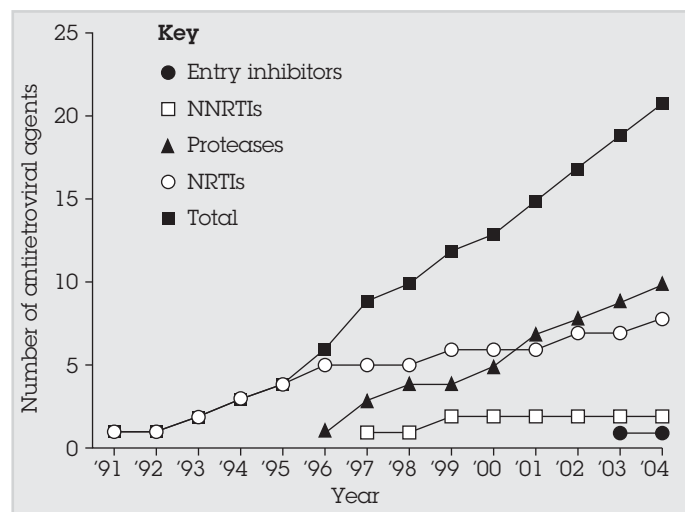
**Figure 2:** ICONA study. Causes of drug or therapy discontinuation among patients on first-line highly active antiretroviral therapy.

increase treatment options not only for patients starting therapy for the first time but also to increase treatment options for those who are treatment-experienced.

### Old drugs: new formulations

New formulations of existing drugs promise more convenient dosing. Two new fixed-dose combination antiretrovirals are now licensed. GlaxoSmithKline's Kivexa, which combines lamivudine (3TC) and abacavir and Gilead's Truvada, which combines emtricitabine (FTC) and tenofovir disoproxil fumarate (tenofovir) in a single tablet taken once daily.

The two component medicines in Kivexa are well established and have been in use since the 1990s; both have recently been re-approved for once-daily dosing following clinical studies that showed the one-a-day regimens were as effective as the earlier twice-daily dose. The efficacy and safety of abacavir versus zidovudine (ZDV) in antiretroviral therapy-naive adults with HIV-1 infection (CNA30024) study found that 3TC/abacavir/efavirenz was not inferior to 3TC/ZDV/efavirenz in treatment-naive patients [2]. The Gilead 934 study compared Combivir (3TC and



**Figure 1:** Number of currently available antiretroviral agents. NRTIs, nucleoside reverse transcriptase inhibitors; NNRTIs, non-nucleoside reverse transcriptase inhibitors.

ZDV) with efavirenz versus tenofovir and FTC with efavirenz. The data for 24 and 48 weeks have been presented; after 24 weeks, the proportion of trial participants with a viral load below 400 copies/ml was 87% in the FTC/tenofovir group and 78% in the 3TC/ZDV group. This difference was statistically significant. The 48-week data support the earlier results and have shown that tenofovir/FTC was better tolerated, with fewer discontinuations than in the 3TC/ZDV arm.

## New drugs in development

There are several new anti-HIV drugs in development that are now being examined, or will soon be tested, in major clinical trials in the UK. Only time will tell how many survive the clinical trial process and become licensed.

### *Nucleoside reverse transcriptase inhibitors*

Reverset is a second-generation nucleoside analogue. It has only been studied in the early clinical trial phases (I and II). At the Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC) in November 2004 results were presented from a 10-day phase I/II trial of Reverset monotherapy in ten treatment-experienced patients; eight received Reverset, two received placebo. The average reduction in viral load among those receiving the drug was 0.8 log units, and four of the eight achieved viral loads below 400 copies/ml [3]. Whilst there are limitations on the conclusions that can be drawn from these phase I/II trials, these numbers are encouraging and larger phase II trials are ongoing.

### *Non-nucleoside reverse transcriptase inhibitors (NNRTIs)*

TMC-125 is a second-generation NNRTI being developed by Tibotec. Several dosing and efficacy studies have been presented at conferences (see below) and results show significant reductions in viral load after just 1 week of treatment. Virus with high-level resistance to efavirenz and nevirapine is susceptible to TMC-125, which is now in phase II/III development.

Tibotec are also developing TMC-278. Data presented at the 12th Conference on Retroviruses and Opportunistic Infections (CROI) meeting this year demonstrated that it also appears to work against multiple NNRTI-resistant mutations up to as many as eight mutations with a half-life of 38 hours and potentially active metabolites [4].

Also presented at the CROI meeting this year, were preliminary data on another new NNRTI being developed by Boehringer Ingelheim, BILR 355BS. The agent showed a good activity against wild-type and resistant HIV but with a half-life of 2.5 hours it requires ritonavir boosting (100 mg once daily) to achieve a half-life of 16–17 hours [5,6].

### *Protease inhibitors (PIs)*

TMC-114 is another compound by Tibotec. This has been evaluated in two large multicentre, international studies in a group of triple class-experienced patients [7]. Each group of patients had a median of 18 PI mutations. A planned interim analysis at 24 weeks showed a significant reduction in viral load in the TMC-114 arm compared to the control arm, and no significant changes were seen in markers of liver function or lipids.

The nearest of all the new agents to licensing is tipranavir from Boehringer Ingelheim. At CROI this year, 24-week data were shown from two large studies of tipranavir. These were phase III, multicentre, randomised, open-label studies of standard of care containing either tipranavir 500 mg boosted with ritonavir 200 mg twice daily or a comparator ritonavir-boosted PI. There was heavy exposure to antiretrovirals in both arms with a median exposure to four PIs, although over 45% of patients had received more than five PIs. At week 24, 41% of the ritonavir-boosted tipranavir arm achieved a treatment response versus 19% of the comparator ritonavir-boosted PI arm ( $P < 0.0001$ ) [7].

Two other PIs demonstrating activity against PI-resistant isolates are 640385 from GlaxoSmithKline and AG-001859 from Pfizer. These are about to go into phase II/III clinical trials in treatment-experienced patients.

## New drugs: new targets

### *Co-receptor blockers*

CCR5 is a major co-receptor for HIV, and CCR5 inhibitors are the first new class of drug since the entry inhibitors, such as T20 (Fuzeon) (Figure 3). UK-427,857 (maraviroc), which is under development by Pfizer, blocks the binding of HIV's glycoprotein gp120 to the CCR5 receptor and so may be able to prevent CD4 T-cells from becoming infected with HIV. UK-427,857 has been administered to around 400 individuals and is currently in phase II/III development with treatment-naïve and experienced patients. Whilst it is too early for any data to be presented from those studies, data from early phase II studies demonstrated around a 1.5 log decrease in HIV RNA. Drug levels are reduced by 50% when food is co-administered and there are interactions with several other antiretrovirals induced by CYP3A4 polymorphisms.

Two other CCR5 inhibitors currently in development are Schering-D (417690) from Schering Plough and GW 873140 from GlaxoSmithKline. Schering-D has a long half-life, is boosted by ritonavir and acts in synergy with existing compounds; again a 1.5 log drop in HIV RNA was found after 10 days of monotherapy in previous studies. This drug is also in phase II/III development. GW 873140, which has been given

to around 40 patients, is now in phase II development and produces a similar viral load decrease to the other molecules mentioned above.

#### Attachment blockers

BMS-488043 has previously demonstrated antiviral activity in HIV-positive subjects. It binds to gp129 preventing HIV binding to CD4 receptors [8].

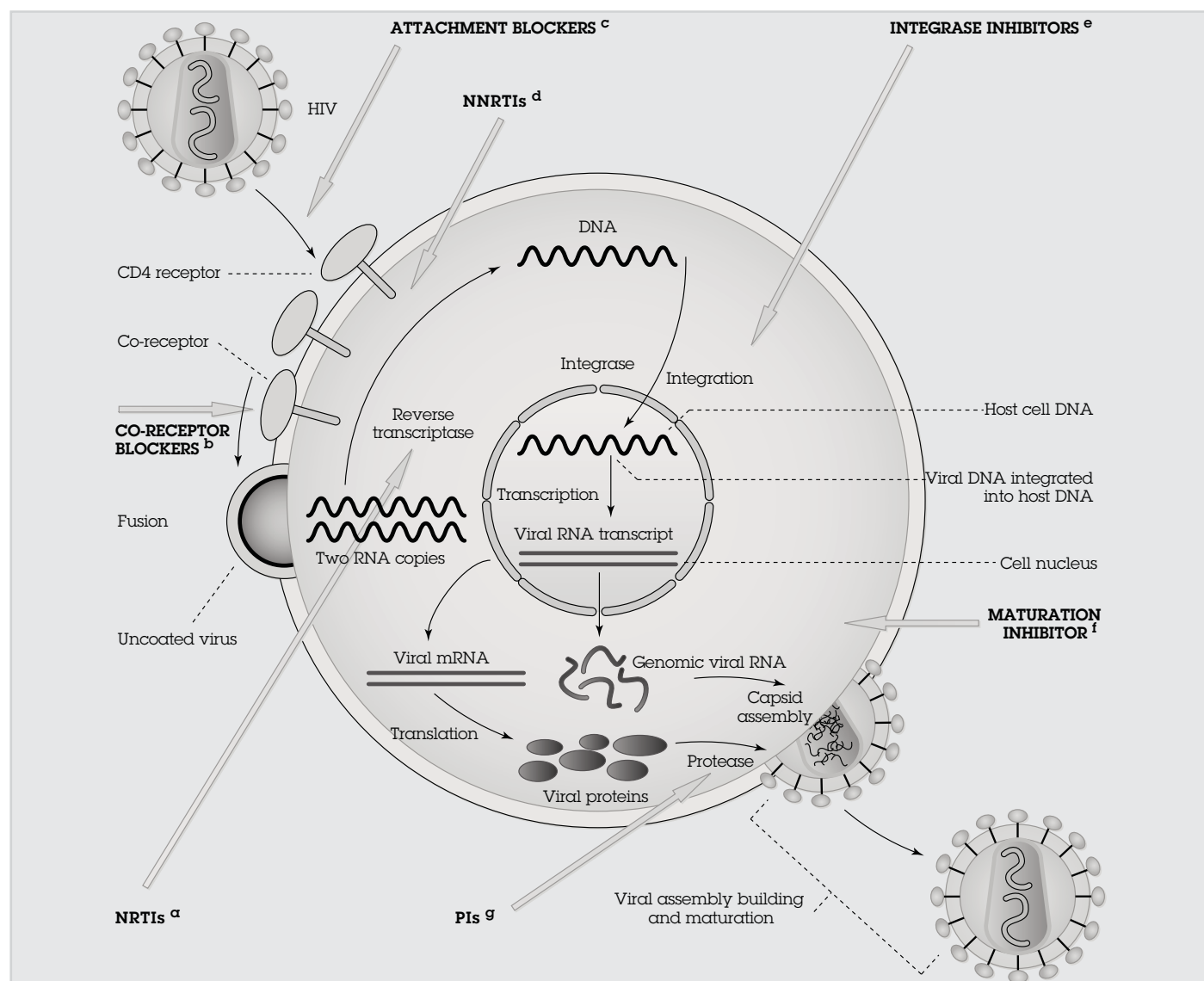
### Maturation and integrase inhibitors

There are also other new drugs in early development for the treatment of HIV with novel mechanisms of action, such as maturation and integrase inhibition (Figure 5). These compounds are earlier in their development and it is likely to be a few years before they are in phase II/III development. However, *in vitro* data have demonstrated that some of the compounds appear to be synergistic with a range of reverse transcriptase inhibitors, so making them a particularly attractive proposition for development.

### Conclusion

Many of the compounds discussed appear to have significant advantages over the drugs that we currently use and some offer a whole new generation of anti-HIV treatments. Some hold out significant promise for those who have exhausted their therapeutic options. However, it is worth noting that these new drugs are still being tested and will not be available until extensive phase III studies have been carried out, meaning their eventual arrival into widespread clinical use could be 2007 or even later.

Clinical studies for treatment-experienced patients are slow and difficult to recruit to. Therefore, if you are managing a patient who is treatment-experienced with limited treatment choices, it may be worth considering that some patients may be eligible to enter a clinical trial. The location of HIV centres participating in clinical trials can be found at [www.nam.org.uk](http://www.nam.org.uk). It may offer the patient access to potentially new therapies and help



**Figure 3:** Viral life cycle and mode of action of new drugs. *a* Truvada, Kivexa, Roverset; *b* UK-427, 857, GW 871340, Schering-D; *c* BMS-488043; *d* TMC 125, TMC 278, BILR 355BS; *e* L-870810, FZ41; *f* PA-457; *g* tipranavir, TMC-114, GW 640385, AG-001859. NNRTIs, non-nucleoside reverse transcriptase inhibitors; NRTIs, nucleoside reverse transcriptase inhibitors.

ensure that new anti-HIV drugs are made available to all as quickly and efficiently as possible.

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# How the recent changes in HIV treatments have affected the role of community nurse

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## Introduction and background

In late 1994, I left a post as HIV Liaison Nurse in a teaching hospital to take up the role of Clinical Nurse Specialist HIV, in what was then a community trust. The HIV liaison post linked hospital and community care, mostly working with HIV-positive patients in the community. Because of the nature of the work, I had been waiting to join the English National Board course on Care of the Dying Patient but by the time I had settled into the new post, the needs of patients were changing and I never re-applied for that course.

Clearly, not everybody living with HIV today has benefited to the same degree from the introduction of highly active antiretroviral therapy (HAART). There are patients who are diagnosed late and others, unable to tolerate HAART, who have multiple resistance to antiretroviral drugs, permanent disability caused by HIV-related illness and other problems affecting long-term health. Long-term survival with HIV can have particular psychosocial impacts. There are patients, who expected to die prematurely, but who are now facing difficult decisions about a future, taking HAART for many years. For some, this has opened up possibilities but for others there are considerable uncertainties including the risks of coming off benefits, employment and fears about future health. And people with HIV are still dying, albeit in much smaller numbers than in the late 1980s and early 1990s.

My caseload reflects changes in the national demography of people living with HIV; the proportion of my patients who were born in sub-Saharan Africa has increased considerably in recent years. The effects of this, including specific immigration and asylum issues such as stigma, displacement, cultural health beliefs and mental health problems, are beyond the scope of this article.

## Year of treatment breakthroughs

The year 1996 has been termed 'the year of treatment breakthroughs' in the National AIDS Manual [1]. Landmark changes included the introduction of viral load testing and the licensing of protease inhibitors. With protease inhibitors came combination therapy: three or more antiretroviral drugs taken together as HAART in order to achieve sustained suppression of HIV, which itself could now be measured and monitored thanks to viral-load testing. The epidemic had seen periods of short-lived optimism before, particularly with the introduction of the first nucleoside reverse transcriptase inhibitors, zidovudine, didanosine and zalcitabine. However, for the first time in the epidemic, there was a sustained sense of optimism, beyond the short term, that affected both clinicians and people living with HIV.

The phrase, 'people living with HIV' has always held a particular significance. Shilts [2] described early AIDS activists in the USA who 'were sick of being called AIDS victims, because the semantics implied that they were passive and helpless at a time when they wanted to fight actively to regain their health. They were tired of

being called AIDS patients because most of them were not in hospital. They wanted to be people with AIDS or, just 'PWAs'. The affirmative 'people living with HIV' took on an even greater significance after 1996. The prospect of living healthily and lengthily with HIV seemed more achievable than ever before.

### Role of the community nurse before 1996

Prior to 1996, patients with advanced HIV disease would be discharged from hospitals requiring a variety of technical and/or intensive interventions. For example, patients with cytomegalovirus (CMV) retinitis had semi-permanent intravenous lines (e.g. Hickman lines and Portacaths) for regular infusions, others could only maintain nutrition through percutaneous endoscopic gastrostomy (PEG), and syringe drivers were commonplace for those with pain and terminal disease. The role of the HIV community nurse often involved close collaboration with district nurses, teaching them, patients, partners and families how to maintain and use various intravenous lines. Flexibility and resourcefulness would see coat hangers deployed to hang infusion bags and intensive interventions in the most unpromising and isolated locations. HIV community nurses were often seen as a specialist technical resource for generic community nurses, a role which has diminished along with the regular use of such interventions. The ability to react quickly to the discharge of a patient, who was in and out of hospital or who wanted to die at home, was frequently tested.

Another large part of the role of the community HIV nurse in those days involved preparing for and dealing with dying and death. Where now there are leaflets on all aspects of HIV treatment, prior to 1996 they addressed the needs of the day: writing living wills, bereavement and dealing with funerals. With no prospect of a sustained reversal of disease progression, community HIV nurses spent time in patients' homes, discussing matters of life and death. In terminal illness, community nurses would advocate on behalf of patients, to ensure that, wherever possible, their wishes were respected. Again, the role was often one of care coordination and acting as a resource to others; for example, working with Macmillan nurses and district nurses, arranging the discrete collection of clinical waste and knowing about 'green burial'. I sometimes say to groups of nurses in training that, compared with the pre-HAART era, I rarely attend funerals nowadays, a positive reflection on the effect of new treatments.

### Role of the community nurse since 1996

Since 1996, with roughly two-thirds of people living with HIV taking HAART [3], the needs of patients have changed. Domiciliary treatment of major opportunistic infections and of terminal illness is a rare event, superseded by the need to support adherence to HAART. The British HIV Association's guidelines on

adherence stress the importance of a multidisciplinary approach that includes the effective deployment of community nurses [4]. Community HIV nurses are now expected to have a good understanding of antiretroviral therapy, drug interactions, adherence and resistance. Environmental and social factors, such as housing, employment, relationships, drug and alcohol use, and immigration status, play an important part in determining a patient's ability to adhere to medication. Community nurses have the advantage of being able to assess patients in the reality of their own homes, where barriers to adherence may be all too visible and where patients may be more able than in the clinic to disclose any difficulties that they may be experiencing with their medication. Simply seeing people in their own environments allows a realistic assessment of their ability to follow the instructions that they receive in the clinic. Adherence plans can then be tailored to suit their real worlds. For example, if medication is hidden from others in the home in order to prevent inadvertent disclosure of HIV status, community nurses can address concerns about the effects that this may have on remembering doses and support adherence accordingly.

Mental health problems, particularly depression, which may affect adherence to HAART, may be more apparent in people's own homes. Community nurses may have more time for assessment, intervention and referral than colleagues in busy outpatient clinics. There may also be a greater understanding of community-based services such as community mental health and voluntary organisations.

### Conclusions and future role

My experience of community HIV nursing in recent years has included a broadening of the complexity of some patients' health needs. With the tools to control HIV for many years, other health needs have become more prominent; for example, stopping smoking, heart disease and cancer. Where once pregnancy was positively discouraged in some quarters, working in multidisciplinary teams to support pregnant women on HAART is a regular part of the casework.

Looking to the future, HIV care seems to be moving towards a chronic disease-management model, promoting self-care and management through multidisciplinary team-working and effective use of information. Although today, people with HIV may have different needs, the advantages of assessing patients in their own homes have not changed with the introduction of HAART. As a community nurse, I see patients in the reality of their day-to-day lives. I have nurse-patient relationships that last for many years. The role of the HIV community nurse as a resource continues through training and multidisciplinary working. Instead of treating advanced HIV disease and dealing with dying, HIV community nursing care is now more commonly focussed on long-term survival, sexual health, HAART,

adherence and securing long-term health as HIV care moves towards a chronic disease-management model.

## Acknowledgments

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# The long-term psychological impact of living with HIV

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## Introduction

The aim of this article is to identify and explore the psychological issues affecting all people living with HIV in the long term. Before doing so, it is perhaps useful to clarify and offer some definitions of the people who are affected in this way. A considerable number of reports in the HIV literature make reference to long-term survivors of HIV [1] which generally refers to people who have been living with HIV for over 10 years, with some of the longest survivors now having been infected for over 20 years. Long-term non-progressors is also used to refer to people who have lived with the virus for a number of years and for whom the virus has not significantly progressed; they therefore often have stable CD4 and viral load counts without treatment with antiretroviral therapy [2]. In this article, long-term survivor refers to anyone living with HIV in the long term, including non-progressors.

## The context of diagnosis

It is important to consider the context of the lives of long-term survivors, the majority of whom were diagnosed in the 1980s and early 1990s. This was a time when there was a significant amount of fear, panic and hysteria surrounding HIV, which was exacerbated by ignorance and misinformation. In this era, a positive HIV antibody test was often seen as a 'death sentence', associated with the fear of close or imminent death. This was largely due to a lack of effective HIV treatments, compounded by limited medical knowledge of a relatively new illness.

The developments of the mid 1990s and the advent of triple combination therapy have had a significant impact upon both the quality and

quantity of life for many HIV-positive people [3]. There is a wealth of data citing the benefits of highly active antiretroviral therapy (HAART) upon morbidity and mortality, which has changed the perspective of HIV from a life-threatening illness to a chronic condition [4]. For many long-term survivors this phrase negates the context of their diagnosis and the huge psychological impact of this upon their lives.

The stigma, prejudice and discrimination associated with HIV are well documented [5]; these factors can permeate all aspects of the lives of HIV-positive people. Some suggest that in 2005 these issues are much less of a problem, although this is not my experience and is substantiated by personal testimonies from clients who feel they have seen little improvement in attitudes over the last 20 years.

Many clients describe feeling branded or marked by HIV infection. This adversely affects their self-esteem; they often feel dirty or contaminated, which increases feelings of guilt and shame regarding their diagnosis. This compounds difficulties regarding disclosure of HIV status and leaves individuals isolated, creating secrecy and 'cover stories' about their situation. Many people fear disclosure of their status because of the risks of rejection.

Individuals with HIV often feel judged by others, with judgements made about their morals and lifestyles, particularly sexuality and drug use; this fosters an 'us and them' attitude, which psychologically segregates HIV-positive people as different and often seen to be deserving of their situation. This discrimination serves to differentiate, whereas in reality much infection is acquired through unprotected sex, which is clearly a mainstream activity demonstrated by high levels of

sexually transmitted infections and unwanted teenage pregnancies in the general population [6]. The discrimination is often perpetrated by family and friends, increasing feelings of hurt and isolation as well as destabilising the foundations of previously supportive relationships. This stance can disseminate to the wider community if an individual's HIV status becomes known, and can result in social exclusion in employment, housing and relationships; especially when there is contact with children [7].

One of the most tangible aspects of HIV infection is the uncertainty; uncertainty about disease progression and prognosis, uncertainty about responses and reactions of others and uncertainty about the future and the securities many of us take for granted. This uncertainty can result in feelings of powerlessness and loss of control, with a loss of sense of purpose and meaning, affecting a person's motivation and ability to plan and set goals. Following diagnosis, many long-term survivors were advised to prepare both practically and emotionally for their death; for many they now struggle to adjust to the concept of living and remain focussed on preparing and waiting for death.

Bereavement and loss is commonly experienced by people with HIV, often with an increased incidence correlating to the longevity of their own HIV infection. Many people have experienced multiple bereavements, including partners, children and close friends. Their experiences of grief and loss can be compounded by feelings of 'survivor guilt' which can exacerbate their fear and anxiety about their own mortality. Losses are experienced not only in terms of bereavement, but also often with multiple losses in most aspects of their life including health, appearance, finance, housing and employment. One of the greatest losses can be loss of choice and control over their lives; particularly in relation to antiretroviral treatment, as people often feel their only choices are treatment or death.

## Mental health and HIV

Mental health difficulties are increasingly being recognised as a significant issue for many people with HIV [8]; with an increase in incidence and complexity associated with the duration of living with HIV. Many clients fear 'losing their mind', with many aware of the potential to develop HIV-related brain impairment or 'AIDS dementia'. A range of mental health difficulties can be experienced, including depression, anxiety and coping and adjustment disorders [9]. Physiological problems such as lipodystrophy can adversely affect body image, self-esteem and relationships, compounding other psychological issues. For those diagnosed as having a mental illness, there is the double jeopardy of having both HIV and mental illness, exacerbating stigma, prejudice and discrimination. Suicidal ideation is not uncommon [10] as the

burden of living with HIV takes its toll and individuals often feel they would be better off dead; for some, completed suicide is a way of regaining control and making a choice to end their life.

Sexual dysfunction is common in the general population, with an increased incidence in individuals with HIV [11]. This can include lack of desire, sexual aversion or arousal, erectile, orgasmic, ejaculatory and sexual pain disorders; the causes of these can relate to underlying physiology due to HIV, antiretroviral treatments or mental health problems, for example depression or impotence arising from the side effects of antidepressant medication. Fears about HIV transmission and condom use can affect both performance and pleasure, which can compound difficulties with low self-esteem and body image; this can become a vicious circle.

Long-term survivors have often experienced progressive, deteriorating health. They often liken their situation to being on a roller coaster with ups and downs of tests and test results, never quite knowing what to expect and always feeling unsure of what awaits them around the corner. Health problems can be perceived as 'minor' by health professionals because they are not life-threatening. However, in reality these 'minor' problems, such as nausea, diarrhoea and herpes, are often distressing and debilitating, consequently they can significantly affect the functioning and quality of life of individuals. In addition, medical results such as CD4 count and viral load may be good on paper, but may not reflect how individuals experience their daily life, as they often try to make sense of why they feel unwell, when medically 'nothing is wrong'. In particular for long-term non-progressors, there can be a sense of waiting for the inevitable, anticipating at some point that their condition will progress. For some the choice of taking antiretroviral therapy feels like delaying the unavoidable and may result in the decision not to take combination therapy. Concerns about illness and treatment side effects are often discussed in relation to the dilemma of quantity versus quality of life, a dichotomy for most. Not surprisingly, the longevity of living with HIV has a cumulative effect, with many individuals experiencing fatigue; fatigue from the virus, fatigue from antiretroviral side effects, fatigue associated with psychological difficulties, fatigue from hospital appointments and fatigue from the psychosocial impact of living with HIV.

## Social context

It is important to consider the social context of HIV and the changes that have occurred in the last 20 years. In the early 1980s, AIDS was classified as a terminal illness and with this came an automatic entitlement to various social security benefits, which afforded some financial security. Changes in treatment for HIV have affected its classification; it is

now often viewed as a chronic condition. This has significantly affected benefit entitlements, with problems applying for and accessing these, resulting in financial hardship for some individuals. In addition, there is a disparity among those with HIV infection in relation to the benefits received, some of which relates to the era in which they were diagnosed. Even those receiving benefits often feel insecure, with regular reviews of entitlement and changes in legislation resulting in fear of benefit withdrawal and anxiety about having to return to work. Many long-term survivors previously stopped work or study because of health problems and their poor prognosis. Now they face returning to work or study, with difficulties explaining their years of 'absence' which may force disclosure of HIV status. Concerns about loss of skills and confidence, worries about health limitations, difficulties attending hospital appointments, conflict with disclosure issues for occupational medicals and difficulty finding a sense of meaning and purpose in their work and ambitions in the context of their HIV diagnosis can all impact upon possible employment.

Relationships pose many challenges and difficulties. The debate of whether or not to disclose your HIV status is a major dilemma for most people. The timing, wording, who to tell and how to tell must be some of the most frequently considered questions for people with HIV; unfortunately there are no clear answers, only individual choices. Most people with HIV have some regrets about their disclosure choices, often having told too many people too soon, and later facing the impact of this, with confidentiality often spiralling out of control and with no means of withdrawing the disclosure. People have faced hostile reactions from family and friends, being ostracised and rejected, assaulted or condemned; these real experiences result in fear of disclosure and consequently a huge amount of secrecy about diagnosis. Unfortunately, this secrecy can result in isolation and a lack of support. Relationship difficulties are further compounded by low self-esteem, poor body image, lack of self-confidence and sexual dysfunction. Difficulties about reproduction also pose dilemmas for those wanting a family: risk of infecting your partner in sero-discordant couples; risk of super-infection in serocordant couples; worries about HIV status of the child; difficulty accessing fertility treatments, for example IVF and sperm washing; and future concerns about parental care and children being orphaned. For some, the burden of these dilemmas results in a decision not to have a sexual relationship and/or not to have a family – for many this thwarts a fundamental desire to care and be cared for and to reproduce.

In addition to the issues discussed, there can be particular difficulties for asylum seekers and refugees. These include difficulty accessing legal support and assistance, exclusion from benefits and

services, limited knowledge of systems and language barriers. For those who are granted leave to remain, they often feel trapped in the UK and unable to return home, which ostracises them from family, friends and their culture. In addition, there may be guilt about the ability to access treatment and care, particularly if they have close family or friends infected with HIV in their country of origin.

For long-term survivors with HIV, most will have witnessed many changes in treatment and care in the last 20 years; this is equally true about changes in service provision and delivery. The days of ring-fenced money for HIV/AIDS are long since gone, with most areas and services providing care and treatment reporting a lack of funds and resources. HIV is subsumed within sexual health, with HIV specialists expressing concern that HIV issues are being lost among the many other sexual health priorities, such as chlamydia, unwanted teenage pregnancies and syphilis outbreaks. Much of the funding utilised for HIV services is monopolised by the huge costs of antiretroviral therapy (approximately £12,000 per patient per year). In reality this leaves little, if any, funding for psychosocial care. Nationally there are few specialist mental health services for HIV-related mental health problems outside the larger centres such as in London. Generic mental health services usually lack the specific knowledge and skills to work with HIV and in reality neither have the time nor resources to address this need when mental health services are also experiencing demands on services which far outweigh resources. Perhaps of more concern, is the general perception that HIV is 'no longer an issue', with its declassification to a chronic condition and worrying perceptions that antiretroviral treatment is a cure for HIV [12].

## Conclusion

To summarise, there are increasing numbers of long-term survivors living with HIV, which is mainly attributable to the advances in antiretroviral treatment. These individuals often experience a complex range of biopsychosocial difficulties, permeated by stigma, prejudice and discrimination. The likelihood of also experiencing mental health problems increases with the length of living with HIV.

HIV involves many challenges, perhaps the greatest of which is to continue to challenge attitudes to reduce fear and ignorance. There is also a great need to raise awareness of mental health difficulties experienced by so many people with HIV and to ensure provision of, and access to, specialist mental health services to meet these needs. In addition, mental health specialists can provide support and education to other health and HIV workers to enable them to provide psychological care with the knowledge of how and when to refer issues on to specialist services.



On 11 September 2001, 2,792 people died in the New York Twin Towers disaster; on this same day, and every day since then, 8,000 people have died from HIV/AIDS.

HIV must stay on the health and political agenda as a priority and nurses and other healthcare professionals have a responsibility to ensure that this happens.

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- access to grants and scholarships for support to undertake research, travel and conference attendance;
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**Nicky Perry, Chair, NHIVNA, Brighton**



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